Unmaking Responsibility

Unmaking responsibility: patient death and face transplantation

Studies of responsibility are increasingly common in anthropology and the social sciences. The concept of responsibilization has proved influential to this corpus of scholarship. Recently there have been a number of calls to move beyond such intellectual engagement with responsibility, which focuses on the devolution of responsibilities from the apparatus of state government to individuals. According to approaches that demonstrate "competing responsibilities" (Trnka and Trundle 2014) and "structures of responsibility" (Ferguson 2012) this literature risks obfuscating corollary modes of doing and distributing responsibility in the contemporary. Building on this literature, I present an analysis of patient death in face transplantation to argue that we need to pay attention to how responsibility is "unmade". In doing so, I argue for a new mode of studying responsibility that pays attention to when questions of responsibility are discursively unmade and ultimately obscured.

Social science engagements with responsibility have demonstrated how the call to be responsible and the devolution of responsibility from state government has penetrated the realm of biopolitics, resulting in new forms of individuality (Adam 2005; Martin 2009; Novas and Rose 2000), community (Epstein 1998; Rabeharisoa and Callon 2002), and citizenship relations (Jasanoff 2012; Petryna 2002; Rose and Novas 2005; Rapp, Heath and Taussig 2008). Others have moved beyond analysis of the public realm to examine responsibility as a productive force in the shaping of relations between kin (Gibbon 2007) and engaged in their own conceptual dissection of the notion of responsibly by exploring obligation in relation to the notion of care (Mol 2008). My analysis pays attention to the consequences of such dissection when it occurs outside of the conceptual realm of scholarship concerned with articulating how notions of autonomy and choice pervade the public and private realm.

Studies of responsibilization emphasize a trend within advanced liberal democracies that has seen individuals increasingly become responsible for what previously, and unquestionably, were duties of the state. As Nikolas Rose (2007:3) writes, this is a shift that has "involved a reorganization of the powers of the state, with the devolution of many responsibilities for the management of human health and reproduction that, across the twentieth century, had been the responsibility of the formal apparatus of government." Rose (2014) himself is one of a number of authors that have raised concerns about the focus of this shift within the social sciences. These authors question the focus on responsibilization as the preeminent mode of understanding responsibility, asking us to consider it "alongside relations of care and social contract ideologies" and to understand these "three modes of inter-relationship… as underlying the 'competing responsibilities' inherent in contemporary social life" (Trnka and Trundle 2014: 1).

But what about when responsibility is seemingly absent? In my study of face transplantation I have been forced to consider instances where responsibility would otherwise be but is not discussed, and what is spoken about in its place. These are instances of potentially preventable patient death in biomedical practice. Through this consideration, I have come to understand responsibility as a product forged at the meeting of diverse social and techno-scientific components, and as something that is open to being remade and unmade. When surgeons discuss patient death in medical publications they do so in a way that discursively shifts responsibility for fatality

away from the operation – that is, from the face transplant the patient received – and moves it into a space outside immediate biomedical agency.

Importantly, this discursive play entails a separation of what Paul Ricoeur (2003) identifies as the two components of "responsibility" – imputation (causes and consequences) and accountability (affect and understanding). This separation is central to the mode of unmaking responsibility that I describe; the broad consequence of this unmaking is akin to what anthropologist James Fergusson (1990) has called "anti-politics" in that it pre-emptively closes down debate about inherently political questions. In this example, the question is: Who and / or what is responsible for patient death? In Ricoeur's (2003) semantic analysis of responsibility, he shows that the term emerged in the 19th Century as an attempt to synthesize analytic problems surrounding the separation of imputation and accountability. The result was (1) a coupling of juridical and moral understandings and (2) the related belief that individual's are not only responsible for there own actions, but also for other people and for valuable objects. "The displacement then becomes a reversal: one becomes responsible for harm because, first of all, one is responsible for others" (Ricoeur 2000: 29). In reports on patient death in face transplantation, cause and consequences are separated from (human) accountability. Instead of asking: Who and / or what is responsible for patient death? reports focus on cause of death in a manner all but divorced from questions of accountability.

This results in situation where no one is responsible for harm, for the wellbeing of the other, because responsibility itself is discursively destroyed in and through biomedical speech acts and the ensemble of components that is face transplantation. This observation echoes previous accounts of the importance of "strategic ignorance" (McGoey 2012) and "knowing not to know" (Giessler 2013) in biomedical contexts (see also Taussig 1999). These accounts detail the mobilization of unknowns as a method for producing authority and commanding resources in the face of unsettling information that could stymie scientific progress or result in liability or guilt in the aftermath of deleterious biomedical events. While sharing a concern with the reproduction of legitimacy in the face of medical and scientific controversy, my analysis focuses on the character and value of the knowledge that is made following adverse events, that is, on "knowing how to know". Thus, while McGoey (2012: 570) emphasizes "the deliberate effort to preclude, obfuscate or deflect knowledge from emerging" as central to institutional efficiency and the denial of liability, for example, I am interested in how epistemic practices discursively recalibrate the relations between human and non-human actors in order to enable a desired future. In the case at hand, this recalibration takes the form of boundary work that limits what is and is not "face transplantation" and the future is that of the nascent biomedical field.

Mode of Analysis

I analyze reports and discussions of patient death as part of my research on the field (author 2013, 2014a, 2014b) in which I articulate how the face transplant apparatus has remade not only the lives of patients but also the very ways in which state institutions, surgeons, and families make sense of rights, claims for inclusion, and life itself in the contemporary world. This research is based on interviews with reconstructive surgeons, and analysis of policy documents and popular and academic

texts, in which I trace the emergence of the face transplant apparatus. Following Michel Foucault (1980: 194-195), I understand an apparatus to be:

> [A] thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions–in short, *the said as much as the unsaid*. Such are the elements of the apparatus. The apparatus itself is the system of relations that can be established between these elements.

It is attention to "the said as much as the unsaid" surrounding patient death in face transplantation that underlies my mode of analysis and it is this which drew my attention toward the uncoupling of imputation and accountability in face transplantation.

I locate reports of patient death vis-à-vis the delineation of a form of life worth living within the face transplant apparatus. In doing so, I show how concerns with the possibility of patient death played a central role in the assemblage of elements that now make up the field – patient selection guidelines, modes of informed consent, bioethical reasoning, immunological drugs, the concept of "quality of life," technological limitations, statements on the importance of the face for human social and biological wellbeing, transplant organizations. To demonstrate how this apparatus works, I present a genealogy of face transplantation, from initial debates surrounding the operation, which focused on patient death, to (reports on) the current state of the field, and related explanations for patient death. This includes a discussion of the "boundary work" (Gieryn 1999) and acts of "purification" (Latour 1993) that discursively atomizes the ensemble of elements that is face transplant.

The Face Transplant Apparatus

One of the core reasons I became interested in reports of patient death in the field is because the topic was so heavily debated in the years leading up to the performance of the first face transplant in 2005. The possibility of patient death stagnated the field and surrounding debate ultimately shaped the very logics that operate within it and the corollary collection of elements that is, now, face transplantation. Underlying this debate was the concern that face transplantation risks killing patients (my words) who don't have life threatening conditions in order to improve their quality of life. These patients are people with severe facial deformities caused through trauma or illness. The primary cause of this risk, according to experts in the field, are the side-effects of the immunological drugs required to counter the biological response of the patient's body to the transplanted face. These potentially fatal effects emerge from the patient's compromised immune system, and include increased possibility of cancer and systemic infection post transplant.

It is generally agreed that transplanting a composite of bone, skin, and corollary biological material from a brain dead donor to a patient with a severe facial condition can result in surgical outcomes far superior to traditional reconstructive procedures. Everyday reconstructive surgeons move bone, cartilage, skin, and other grafted tissue around the bodies of individual patients. This autotransplantation is a key method of reshaping the deformed or disfigured patients they treat. However, this mode of

surgical reconstruction often results in outcomes that disappoint patients and practitioners alike. By allowing reconstructive surgeons the possibility to truly follow the famous tenant of their sub-specialty – "to replace like with like" – face transplantation offers the possibility to produce surgical results that better mimic the "normal" functional body: eating, speaking, breathing and feeling socially comfortable.

However, critics argued (as they still do) that the potentially fatal consequences of face transplantation, a medical procedure that aims to offer patients with a "non-life threatening" condition an improved quality of life, means that it contravenes the Hippocratic oath to "first, do no harm" and goes against the principles of bioethics. Bioethical reasoning dictates that the benefits of any medical procedure must outweigh the risks. In the early days of face transplantation, in the years before the performance of the first procedure in 2005, the jury was out as to both the risks and the benefits of such a transplant: Is the geneticity of the skin, and thus the likelihood of biological rejection higher for the face than in solid organ transplantation? What about the side effects of immunosuppressant drugs; would more be needed in the case of face transplantation? What are the risks and benefits of living with someone else's facial tissue in place of your own? Proponents of the operation could not and did not answer these questions as a mode for gaining institutional consent to perform the procedure. Instead, they argued that careful patient selection could pull the risks and benefits of face transplantation in favor of its performance.

The technical limitations facing surgeons (the dependence on immunosuppressant therapy) together with the bureaucratic constraints (bioethics) resulted in the delineated a new kind of patient subject: the ideal patient of face transplantation (Author 2014a). Face transplant teams in Europe and the America's successfully argued that by selecting a patient whose particular state of health and suffering is so that they require the procedure while being healthy enough to withstand the biological and psychological effects of the transplanted facial tissue, minimized the risks and increase the benefits of the procedure, aligning it with bioethical and Hippocratic reason. In other words, face transplantation came to depend on finding patients that exhibit certain qualities, whose health exists in a certain balance between normal and pathological: it is in this balance that patients become operable and the procedure ethical – they conform to the very guidelines and arguments that produced them in light of current technological possibilities and limitations (Author 2014b). And it is this balancing of health and illness that ultimately allowed the first operation to take place.

The famous, or, depending on whom you ask, infamous first face transplant operation was performed in Amiens, France in 2005. The infamy of the operation relates to patient selection. For many in the medical world, the world's first face transplant patient, Isabelle Dinoire, was anything but an ideal candidate. A chain smoker whose face was gnawed off by her dog while she law unconscious following an overdose on sleeping pills, Ms Dinoire's particular state of health of suffering allowed local and international critics to raise numerous questions surrounding the motivations of the acting doctors and the ethicality of the procedure (see author 2013). It was not a smooth first act in what was already a story with a long and provocative prelude. Though, despite her ongoing immunological and psychological difficulties, eventually the debate surrounding Ms Dinoire's discussion died down.

At present, there have been multiple attempts to provide a thorough overview of the state of the field. Yet, as bioethicist Karen Mashke (2007) and I (2014a) have both argued, methods for answering fundamental questions such as what constitutes "success" are yet to be produced. At the time of writing (November 2014), a total of twenty-nine face transplant operations have been performed in a collection of countries including France, the USA, Spain, Turkey, and China. Following updates to Federal Health policy, the operation is now governed by national transplant agencies in the USA, which are currently producing a nation-wide database that will be used to assess the field. Below I examine existing reports of the field, paying particular attention to how patient death is discussed. At the time of writing, four patients have died after receiving a face transplant out of the twenty-nine patients that have undergone the procedure.

Patient Death

Following the operation on Isabelle Dinoire in France, a team of Chinese surgeons used transplanted facial tissue to reconstruct the face of Li Guoxing, a thirty year-old man who was disfigured in a beer attack. His surgeon's offered the following comments on his death: "His death was not caused by the surgery. Our operation was a success" before continuing "But we cannot rule out a connection with the immune system drugs" (Lite 2008). In this instance, face transplantation is presented as a singular event; it is limited to the movement of the graft from the donor to the recipient, and the biological acceptance of the graft; it is not presented as (a network) composed of human and non-human actors – bacteria, infection, immunological drugs, medical experts – that requires ongoing management in order to preserve the health of the patient and the graft.

A more complex account was presented in a review of the field that appeared in 2009. In this description the cause of death is patient non-compliance, a non-compliance that is mediated by a non-medical sociocultural system:

> Although the details have not yet been published, this patient died during his third-year post transplant. The patient became *noncompliant* with his immunosuppressive regimen possibly at the advice of a "witch doctor" (nonmedical tribe doctor) and had a very limited social support system in place. He resided in a remote village at a far distance from the hospital. (Gordon et al 2009: 573 *emphasis added*)

In both of these accounts the cause of patient death is not "the surgery." A boundary is discursively drawn around what counts as death by face transplant. The notion of boundary work was developed by sociologist Thomas Gieryn (1983: 782, 1999) to describe the "attribution of selected characteristics to the institution of science (ie to its practitioners, methods, stock of knowledge, values and work organization) for purposes of constructing a social boundary that distinguishes some intellectual activities as 'non-science'." In the case at hand, the demarcation drawn is between what is and is not "face transplantation." This discursive work is accompanied by an epistemic murkiness surrounding exactly what caused Li Guoxing's non-compliance – was it (the unbearable side effects of the) drugs, his own inability to withstand the discomfort they caused, or the "nonmedical tribe doctor".

In this instance, as in the below examples of discourse surrounding patient death, the issue of responsibility does not appear. Better put, it is disappeared, is unmade through the very biomedical presentation of cause of death and delimiting of what is the face transplant. This delimiting involves the distribution of cause and consequences into the network of (non-human) actants and practices that compose the face transplant apparatus. This produces a demarcation between human and non-human causes, which sharpens the divide between what is and is not the face transplant. In the second case of patient death in the field, the cause was reported as "comorbidity" or the patient's related health problems. This was a French patient that died from cardiac arrest after receiving a concomitant hand and face transplant. His surgeons summarized his case as follows:

> On day 33, following surgical excision of infected transplanted tissues, the patient suffered anoxic cardiac arrest resulting from tracheotomy obstruction while being taken from the post operative care unit to the operating room for treatment of massive hemorrhage (septic rupture on a radial bypass). After 5 weeks of intensive care, severe anoxic cerebral lesions revealed by MRI, despite no criteria for brain death, were judged irreversible and led to death on day 65. The left hand had been amputated previously, and the upper part of the facial transplant removed because of its total destruction by the infection. (Lantieri et al 2011:372)

In this example, the patient's death is located in an ensemble of medical procedures (tracheotomy), body conditions (inflammation), and the high-tech medical environment where he is located (the intensive care unit).[i] While there is a partial link to the face transplant procedure, the cause of death is attributed to infection rather than "face transplantation" (see also Khalifian et al 2014).

Similar, the most recent summary of the field tells us that it was not the face transplantation, which included replacing the tongue and jaw, that resulted in the death of Spaniard "Francisco M.G." but his "underlying medical conditions": "The third confirmed death after face transplantation was the result of tumor recurrence in an HIV-positive patient who had previously undergone cancer resection" (Khalifan et al 2014: 3). In this case, the cause of patient death is moved away from the operation an into the (natural) body of the individual – not discussed is the possibility that the tumor recurrence resulted from the patient's artificially lowered immune system, that is the immunological therapy used to manage biological rejection of the transplanted face. And the cause of the most recent death is even murkier than the previous. The only mention of the case that I could find in a medical journal reads: "The last reported death was a Turkish patient who died one year post-operative due to organ failure necessitating removal of the transplanted face" (Roche et al 2015: 100).

At play here is not only a form of discursive boundary work that delimits face transplantation to an operative event. These deaths are situated within a broader apparatus that has produced particular forms of "human targets" – patients whose health and wellbeing allows face transplants to take place as ethical procedures. This ethicality is dependent upon affording the life of patients with severe facial deformities a kind of "negative value": The message is that restoring the anatomy of these persons with a face transplant is so important that it is worth risking death to achieve it, worth sacrificing a life lived with their "abnormal" face. This status of the

face transplant patient as a "sacrificial subject" is implicit in and central to the field. At stake in patient death is the notion of a life worth living that was formed through the assemblage of rationalities, bureaucracies, and technologies that is now face transplantation. Embedded within this notion in an implicit coupling of a good life and broader ideas of sociotechnical progress, which underlie the transplant apparatus in contexts such as the USA (Sharp 2013): Technomedicine is imagined as central to societal flourishing. The limitations of technology risk being exposed if the transplant is rendered a failure and the ramifications of this arguably extend beyond the medical field under analysis because it allows the question to be raised: Is a technomedically-mediated life, with its associated risks, worth living? This question is silenced when death is associated with non-human actants. Meanwhile, patient selection continues to be presented as a panacea to the risks inherent in to face transplantation: the "patient deaths that have occurred reinforce the importance of patient selection for potential non-compliance and underlying medical comorbidities" (Khalifan et al 2014: 3). Who, then, is responsible for patient death in the above examples?

Discussion

The answer is that no one is responsible. If responsibilization refers to the devolution of responsibility from the nation-state then "unmaking responsibility" indicates the dissolving of responsibility itself. In his genealogy of the term, Paul Ricour (2003:11-12) notes the multiple uses of "responsibility" inside and outside of law. In civil law, for example, "responsibility is defined by the obligation to make up or to compensate for the tort one has caused through one's own fault" while in penal law responsibility is "the obligation to accept punishment". Outside of the legal sphere you are both "responsible for the consequences of your acts" and also for those of others "to the extent that they were done under your charge or care". I find it difficult to locate any of these three uses of the term in the case of patient death in face transplantation. This is an outcome of (a) the underlying logics that mediate many forms of experimental biomedicine – "quality of life", bioethics, norms of health and the body – which allow for (b) the decoupling of imputation and accountability. These logics are embedded in and mediate the reasoning of the bureaucratic bodies (Institutional Review Boards, etc.) that in approving experimental procedures plays in important part in minimizing questions of physician or institutional liability (Rosenburg 1999). The discursive making and placing of cause of death is another mode where such minimizing happens.

The ability to attribute responsibility is itself negated in the reports discussed above when the actions of patients and physicians are separated from the cause of death. There is no discussion of who is accountable for patient death, of the possibility of medical negligence in the form of i.e. failure in patient selection. Nor is there talk of what might have been for the patients if they had not received the operation; their death is not presented as a tragic example of lives lost in an experimental biomedical realm but as exemplars of the need to select patients carefully in order to demonstrate the potential and safety of this form of facial reconstruction. In the epistemic murkiness clouding the death of Li Guoxing it was social factors that led to his non-compliance; in the other examples it was the underlying biology of the patient – preexisting conditions – that caused their death, not human action. The unmaking of responsibility that I have written about has important parallels with the shifts brought about through neoliberal policies that stress individual and community empowerment.

As Barabara Cruikshank (1999) has written, a core feature of such "empowerment" initiatives is that responsibility is distributed in a way that it can become difficult, even impossible, to attribute responsibility to any particular actor.[ii] In moving attention to the "distribution" of responsibility in technomedicine, I am suggesting that such difficulties exist as a central resource in the maintenance of biomedical projects.

Moreover, sometimes responsibility disappears in the tactical work that is done to code medical procedures as safe and necessary, when patients die in the context of experimental biomedicine - responsibility is unmade by a form of speech that separates causes and consequences. In face transplantation, this entails aligning successes with the ideal patient, and *vice versa*, so that the cause of medical failure and patient death comes to lie away from the medical procedure. In his writing, Richard McKeon (1990:83) states: "The elements from which the concept of responsibility developed, accountability and imputation, are both external limits put on the freedom of action." Central to this quote is the notion of human agency, as it pertains to the ability to act in a particular manner. Many accounts of responsibility and biomedicine have explored how patients' and practitioners' ability to act are mediated by a collection of social, techno-scientific, and biomedical factors (see Rose 2007). Others have explored the transformation in patient-doctor relationship in the context of neoliberal biomedicine. In medical reports of patient death and face transplantation, agency is sidelined, it is moved outside of the field.

There is of course a tension, here. Patient selection is presented as paramount to operative outcomes, yet in the accounts offered patient death is not caused by the operation itself but by a mix of technological limitations (the need for immunosuppressant therapy), the pre-extant wellbeing of the transplant recipient, as well as the social and biological environments in which they live (that contain such things as bacteria and "tribe doctors"). Focusing on such tensions may lead to a better understanding of responsibility, to one that reveals its *contingency* as a product of complex sociotechnical apparatuses, and to reflection on how we deploy the concept in our own analysis. Viewing responsibility in this way, as something both made and unmade, opens up the possibility that "responsibility" might not be present in a given context; it allows us to enquire into other ways that responsibility is done (or undone), the ramifications of this, and the reasons for its occurrence.

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[ii] I wish to thank Susanna Trnka for drawing this parallel, and for alerting me to Cruikshank's writing.